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California HealthCare Foundation

Commentary

What Killed the Santa Barbara County Care Data Exchange?

By Bruce Merlin Fried, Esq.
March 12, 2007

The Santa Barbara County Care Data Exchange is no more. There was hardly an obituary to note its passing. A fitting tribute might have included phrases like: "ahead of its time" or "potential never realized" or "it was harder than it looked." What might be more valuable than an obit is a post mortem. The challenges that SBCCDE confronted -- many of which were overcome and some of which led to its demise -- are challenges that every care data exchange and regional health information organization should study and address directly. There are many lessons to be learned from SBCCDE's fate.

In early 1998, the Santa Barbara County Regional Health Authority met with Jack Lewin, the president of the California Medical Society, to discuss his call for an electronic health record system with data sharing capacity because the Health Authority wanted to pilot such a technology. Shortly thereafter, the Health Authority, Lewin and leaders from the California HealthCare Foundation met at the Pacific Business Group on Health, and the project was launched. In mid-1999, David Brailer -- subsequently the first National Coordinator for Health IT -- and his company, CareScience -- whose board I subsequently joined -- became involved in the technical design and construction of the project. Ultimately, CHCF invested $10 million in the project.

Brailer and his staff, leaders from the Health Authority, CHCF leaders and others went to work building a consensus within Santa Barbara's clinical community. The care data exchange technology -- a central index, peer-to-peer model -- was in development by CareScience. Things were moving along. Every thing was, as my grandmother would say, hunky-dory. Or so it appeared.

Early Challenges

Then came the first major issue: legal counsel for one of the community's major hospitals raised concerns regarding whether the care data exchange model complied with state privacy laws.

According to Phil Greene, who served as chair of the SBCCDE during most of its life, "We felt if we went to a nationally recognized law firm with a reputation in health law that we could circumvent the concerns and conservative tendencies of every general legal counsel for participating agencies. This ... was foolish on our part."

In the service of transparency, the "nationally recognized law firm" that SBCCDE went to was mine. My colleagues and I were engaged to identify all applicable privacy laws and determine if there were any privacy impediments to the SBCCDE approach. Simply identifying all relevant laws was a tremendous challenge. There were general privacy laws and privacy laws for beneficiaries of different programs, such as Medicaid, state-funded health programs and county-funded health programs. There were privacy laws for patients with various illnesses, such as sexually transmitted illnesses and mental health issues. There were privacy laws to be applied to particular health settings, such as public health clinics. Needless to say, it was a regulatory morass that required a lengthy and expensive legal analysis.

Even then, Greene observed: "The chief counsel and the privacy officer for [an important provider] were going to go very slow on this and do it their way or not at all. Their demands at the end were going to require changes in the architecture of the system." At the end of the day, a path was found through the morass. First hurdle cleared. Even then, early fissures could be seen among the providers.

Greene noted three additional, ultimately fatal problems. First, the care data exchange technology was cutting-edge. The project ran into all of the possible difficulties exploring how the care data exchange might work. "Given that the [care data exchange] was just going to be a switch, and data was to reside and be maintained by the owner, all sorts of expensive interfaces with old legacy technology had to be developed." The technology challenges were more than anyone bargained for.

Second, Greene notes that the substantial financial support from CHCF made the community a passive participant in the whole process. In hindsight, it became clear that the community permitted CareScience to take on many of the responsibilities that properly should have been the community's. While CHCF was making an important investment in developing the care data exchange technology and supporting the community of potential users, that investment allowed the community to put off developing a viable, financially self-sustaining business model.

Finally, Greene observed that "the fact that the project was drawn out so long, eight years from conception to death, made most in the community, mainly the physicians, very cynical about its possible success. This led, of course, to most ignoring any genuine announcements about progress in the final years."

Learning from SBCCDE

There are any number of other issues that were distracting, frustrating, expensive and ultimately contributed to SBCCDE's demise. Crafting user agreements and vendor agreements required making the project legally "real," so real commitments, real responsibilities and rights, and real obligations had to be negotiated, agreed to and captured in legally binding documents. The process of doing that gave rise to new concerns about liability and indemnification in the event that bad data crept into the system or good data was used improperly and, in either case, patients were injured.

Each of us, particularly those working to build sustainable RHIOs and care data exchanges, should carefully study what went right and what went wrong with SBCCDE. There are important lessons to learn from this unfortunate failure. What's clear is that building a long-lasting care data exchange is always harder than it looks. What's clear is that absent a firm community commitment to a shared vision and to doing what it takes to make that vision a reality, success will be elusive.

Hopefully, a more careful and comprehensive analysis of SBCCDE will be undertaken. From such an effort, the entire health IT community should be able to gain insight and vision that will help to build the kind of digitally connected health care community the good people in Santa Barbara were seeking.

CHCF is the publisher of *iHealthBeat*.

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